BRIEF TO THE ROYAL COMMISSION ON NEW REPRODUCTIVE TECHNOLOGIES

Canadian Advisory Council on the Status of Women

Conseil consultatif canadien sur la situation de la femme

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INTRODUCTION

The Canadian Advisory Council on the Status of Women (CACSW) is an independent organization funded by the federal government. The CACSW was established in 1973 on the recommendation of the Royal Commission on the Status of Women and is composed of a maximum 30 members appointed by the federal Cabinet. Twenty-seven part-time members are appointed to three-year terms; collectively, they represent the regional, cultural, occupational, and ethnic diversity of Canada as well as both official languages. The CACSW has three full-time members: the president (appointed to a five-year term) and two vice-presidents (appointed to three-year terms) who represent the eastern and western regions of Canada.

The CACSW's mandate is to bring before the government and the public matters of interest and concern to women. Council members ensure a continuing liaison with women's organizations in their provinces and territories, maintain the CACSW's research agenda, and formulate and adopt Council recommendations on a wide range of issues aimed at improving the status of women. As an agency operating at arm's length from the government, the CACSW reports to Parliament through the Minister Responsible for the Status of Women, thus allowing the Council to maintain a voice within Parliament while retaining its right to publish without ministerial consent.

Since 1973, the CACSW has placed issues affecting women's reproductive health high on its agenda and has made recommendations on abortion, reproductive health clinics, birth planning services, and contraceptive safety and information. More recently, the CACSW has identified reproductive health principles that guide its views on reproductive health and are relevant for discussing new reproductive technologies (NRTs). In recent years, the CACSW has published several documents on reproductive health and NRTs and has drawn upon these sources in the preparation of this submission to the Royal Commission on New Reproductive Technologies.[1]

Biological reproduction has long been a site both of women's power and of women's subordination. Although NRTs currently affect relatively few women, they have the potential for transforming, on a mass scale, the social and biological conditions of human reproduction in the future. Contemporary women thus carry a historic responsibility to protect the interests of succeeding generations of women.

The CACSW regards NRTs with scepticism. This scepticism is conditioned by our awareness of the harm done to women's reproductive health in this century through the disastrous effects of pharmaceuticals and devices such as thalidomide, DES, the Dalkon Shield, and Depo-Provera. Moreover, in the context of contemporary Canadian reproductive health care, women are routinely subjected to multiple unnecessary medical interventions which give rise to iatrogenic complications, i.e., those caused by the process of medical examination or treatment. Thus, the CACSW is concerned about the development of NRTs because they give further power to elements within the medical profession and pharmaceutical industry which have a dubious history and doubtful current record of practice with respect to women's reproductive health.

At the same time, the CACSW empathizes with the desire of involuntarily childless women to conceive and bear children. We support these women's informed choice to use these new reproductive technologies as a means to their goal. Women making such an important decision need access to complete information on NRTs, including procedures, health risks, and success rates. Because many of these technologies are new, the CACSW stresses the need for short- and long-term research which will produce the information needed by women considering NRTs.

Involuntarily childless women who can't be helped by NRTs face hardship: coming to terms with their situation in this society is not easy. Contemporary medicine cannot cure everything. Counselling must be made available to those who bear the brunt of social intolerance regarding any deviation from the nuclear family.

With the support of an increasingly sophisticated medical community, the media have contributed to public misperceptions about NRTs. For example, the Royal Commission's own public opinion research reveals that most people in Canada believe in vitro fertilization (IVF) to be more effective and less costly than it is currently. This is a not unsurprising overgeneralization from the mass media images of the "perfect babies" born through IVF. Strangely, media representations of IVF-associated adverse drug reactions and perinatal mortality are notably absent.

Misperceptions about the status of women in Canada also abound. Much-heralded accomplishments about the "first women this" and the "first woman that" merely serve to underline the early stages of women's independence and struggle for equality. Although women form the majority of Canada's population, they are far from equality. Women lack control over their lives, homes, workplaces, as well as their bodies and their sexuality. Women are underrepresented in positions of social and political power, they are poorer than men, they are the victims of massive social and sexual violence, they lack control over their reproductive freedom, and they are penalized for having and raising children. As well, certain groups of women — including racial minority women, disabled women, Aboriginal women, immigrant women, rural women, and lesbian women — face additional discrimination and inequality.

> Discrimination against women in our society is massive. It is systemic, entrenched in our institutions, and it affects all women . . . The discrimination women experience changes form, becomes more subtle, and continues. Women remain a social underclass, still denied equal status and equal power in society.[2]

In this context, the CACSW has taken the position that it is not sensible to be for or against new reproductive technologies. Women need a framework for discussion of NRTs, more information, and more opportunities for involvement and public discussion and decisions about these technologies.

Basic questions of power and credibility surround the issue of NRTs. Many medical practitioners, including obstetricians and gynecologists, have appeared before this Royal Commission, speaking with the social authority

vested in them as recognized experts in the field of reproductive biology. Although medical experts have valuable clinical and research knowledge in the area of human reproductive biology, as a social group they should not become the dominant interest defining reproductive health and advising on social policy formation in this area. The overmedicalization of pregnancy and childbirth in Canada amply demonstrates the divergence between women's interests and professional interests in matters of reproductive health. The CACSW is pleased that the Royal Commission on New Reproductive Technologies, through its publicity and theme conferences, has encouraged women's public participation in the discussion of NRTs and allied fields. We hope that the Commissioners will hear and take to heart the perspectives of community health activists, women's health groups, women's organizations, midwives, feminist researchers, consumer groups, and women speaking from their experience as patients.

The CACSW agrees with the direction of federal health policy announced in Health and Welfare Canada's 1986 statement, *Achieving Health for All*, which remarked upon "the role of individuals and communities in defining what health means to them."[3] Quoting the World Health Organization (WHO), *Achieving Health for All* went on to characterize health promotion as "the process of enabling people to increase control over, and to improve, their health."[4] The document emphasized the significance of public participation in health promotion, linking such participation with "helping people to assert control over the factors which affect their health."[5]

In contrast, the direction of NRT research, clinical practice, and policy has been shaped principally by the medical profession. Likewise, the criteria which inform research, access, clinical practice, and legal and social policy thus far have been determined principally by the medical profession. Given the potential impact of NRTs on the future of reproductive health, maximum public participation in discussion and debate is necessary. The CACSW urges the broadest popular participation in defining and controlling the meaning of NRTs as they transform previous meanings of reproductive health. In particular, because the majority of the new technologies pertain specifically to women's bodies, the participation of women is essential and should be encouraged at all levels of discussion, policy formation, and regulation.

As with any form of technology, the social benefits and risks cannot be predicted simply by examining the physical product in isolation from the social relations under which it has been developed and sustained.[6] The technologies under consideration by the Royal Commission include procedures used throughout the twentieth century, such as alternative fertilization (artificial insemination) and conventional treatments for infertility. Older and newer reproductive technologies now interact in complex and contradictory ways because of the prevailing social constructions of motherhood, family forms, and genetic parenthood. For example, the desire for children carries heavy normative weight in our culture: voluntarily or involuntarily childless women are often viewed as selfish and deviant. As well, the widespread belief that a woman is not truly fulfilled as a woman without having experienced pregnancy, childbirth, and motherhood places enormous pressure, both external and internal, on voluntarily or involuntarily childless women. Newer conceptive technologies which can bypass infertility may exacerbate this ideology of motherhood, further stigmatizing infertile women and the voluntarily childless. The CACSW is deeply concerned about the future impact of reproductive technologies on the experience of infertility and cultural understandings of childlessness in women.

In vitro fertilization (IVF), embryo transfer (ET), embryo lavage, gamete intrafallopian transfer (GIFT), and alternative fertilization by donor destabilize the relation between genetic and social parenthood.[7] On the one hand, conceptive technologies may be used to link genetic and social parenthood in ways previously impossible for many infertile women and men. On the other hand, the technologies make it technically feasible to draw a set of new social distinctions: ovum donor, gestational mother, social mother, sperm donor/genetic father, social father. Consequently, a widely ramified renegotiation of the meanings of maternity and paternity is taking place in the mass media, in our legal system, and in the lives of those affected by NRTs. In response to the destabilization of genetic and social parenthood, the courts and medical profession have for the most part asserted the normative role of the isolated, single household, one-generational family consisting of one man and one woman acting as social parents to "their" children. The privileging of this family form has not been subject to wide social debate. Indeed, this Royal Commission would perform a useful role by helping to stimulate awareness of the various types

of families and the benefits to be reaped by welcoming this diversity in our society.[8] As Gloria Steinem has said, "Family is not form, family is content".

At the beginning of the 1990s, the meaning of the new reproductive technologies has not yet been fixed in stable social and cultural patterns. The CACSW hopes that the Royal Commission will help construct new and more democratic ways of imagining the social implementation of reproductive technologies. Most importantly, we hope the Royal Commission will help form the political and cultural conditions which will benefit women's experience of human reproduction.

THE NEED FOR GENDER-SENSITIVE ANALYSIS

Women and men have a differential social and biological relation to NRTs, because the vast majority of pharmaceuticals administered in NRTs circulate within the bodies of women only, and most invasive and diagnostic procedures are performed on women and not on men. Because NRTs principally, though not exclusively, affect the reproductive health of women, the Royal Commission must primarily focus its work on women's experiences and perspectives.

Despite the relation of NRTs to women's bodies, infertility services are directed to "the couple" rather than to individuals. Many clinics offer their services only to male-female couples, thereby excluding single or lesbian women: this constitutes discrimination on the basis of marital status and sexual orientation. Couple bias also obfuscates sex- and gender-specific differences in research and in clinical practices. This process of omission can be seen in the following statement given during IVF counselling at the Chedoke-McMaster Hospitals in Hamilton, Ontario:

> In Vitro Fertilization (IVF) may be helpful to some **couples** who are infertile. IVF is not the only way to treat infertility, and it may not be appropriate for some **couples**. IVF can sometimes help **couples** who are infertile from disease or abnormality of the fallopian tubes. It may also be suitable for **couples** who have the problem of a low sperm count.[9] (emphasis added)

This is a stellar instance of gender insensitivity, a frequent problem in sexist research and analysis. Margrit Eichler characterizes gender insensitivity as a problem which "consists of ignoring sex as a socially important variable."[10] The counselling advice offered by the hospitals constructs the male and female relation to IVF as equivalent, to the extent of making itself open to the comical interpretation of the couple as an androgyne with four arms, four legs, and both male and female reproductive systems.

Canadian governmental and paragovernmental reports have focused on socio-legal issues rather than women's reproductive health in their examination of alternative fertilization, contract motherhood, and IVF. Three such reports are the *Ninth Report of the British Columbia Royal Commission on Family and Children's Law*,[11] *Proposals for a Human Artificial Insemination Act* (Saskatchewan),[12] and the *Report on Human Artificial Reproduction and Related Matters* (Ontario).[13] They all have as their overriding interests the rights and role of the husband/common-law spouse, legal rights of the sperm donor, legal status of the child, and the access of unmarried women to infertility services. Thus, the axis of discussion in these reports is the link between men and children, attempting to constitute families with legally recognized fathers responsible for child maintenance and support. Generally speaking, the reports suffer from two frequently occurring problems in sexist research: androcentricity and double standards. The relative invisibility of women in these documents indicates that the texts have been organized from a male perspective: the problem of androcentricity. Double standards arise when identical behaviour on the part of women seeking access to infertility services is judged positively or negatively on the basis of their marital status. Notwithstanding the sometimes valuable analyses found in these reports, from the perspective of women their frame of reference was extremely narrow.

Because of its broad mandate and the scarcity of alternative documents, the report of the Canadian Royal Commission on New Reproductive Technologies will have enormous domestic and international importance. The work of the Royal Commission will supply categories and analyses that set new standards for understanding NRTs and related matters. Consequently, there is a tremendous opportunity to shift the terms of discussion, assisting in the development of greater gender-sensitivity. In light of its future documentary role, the CACSW strongly emphasizes the need for the Royal Commission to adopt the feminist research methodologies outlined in this section. Women's gender- and sex-specific health needs with respect to NRTs must be an essential component of the Royal Commission report. This would be in accordance with both good research methodology and social justice.

BASIC PRINCIPLES

Although the mandate of the Royal Commission on New Reproductive Technologies is wide in comparison to other similar government inquiries, its guiding principles are unknown to the public. Thus it is unclear what premises will inform the analysis and recommendations of the final report. The guiding principles of this CACSW brief have been established by feminist contributions to the understanding of reproductive freedom made in the second wave of the women's movement (1967 to present), in combination with fundamental ideas of women's health groups.[14] These principles, intended to assist the liberation of women in the field of human reproduction, are: the empowerment of women, bodily integrity, informed choice, and equality of access.

The Empowerment of Women

In relation to health, the phrase "empowerment of women" means more than high-quality health care. It also implies care that both enhances women's control over their lives and contributes to their autonomy. This is health care that puts control of all key decisions regarding a woman's health

and reproduction in her own hands and provides all the services, counselling, information, and support to enable her to put her decision into practice. In dealing with NRTs, this principle entails increased control by women acting in their own interests over the direction, development, and regulation of these technologies.

Bodily Integrity

The assertion of the need for women's control over their own bodies has been central to contemporary feminism. Women's bodies have historically been the subject of regulation through government and religious institutions, over which they had little power or say. Women's bodily integrity is undermined by all forms of violence.

As a social and ethical principle, bodily integrity claims that women must have the power of autonomy and individual self-determination in those bodily processes which are capable of being socially controlled and regulated. In the sphere of human reproduction, the principle of bodily integrity leads to demands for safe and effective birth control, access to maternity care, choice on abortion, and the ending of sterilization abuse.

With respect to reproductive health care, it is essential to assert that individual women should have absolute power of decision with regard to medical intervention in their own bodies. Because the fetus/implanted embryo occurs inside, and is dependent on, a woman's body, all considerations as to the status of the embryo/fetus are irrelevant in discussions of forced medical intervention during pregnancy. The pregnant woman is the appropriate advocate for the fetus and her decisions regarding her internal bodily processes during pregnancy and childbirth should be respected.

Informed Choice

Consumers have criticized obstetrics and gynecology for failing to circulate information regarding the risks, benefits, and alternatives to recommended treatments. Women want more information and explanations of alternative treatment forms and methods in pregnancy and childbirth. For example, it is not clear on the basis of current research that in vitro fertilization/embryo transfer is more effective in treating idiopathic (of unknown cause) female infertility than are conventional treatments. Women with idiopathic infertility need this information in order to make an informed choice about other options.

Informed choice is predicated on counselling methods which give the health consumer sufficient information and power to accept or refuse treatment, to choose among caregivers and caregiving approaches, and to select a desired course of treatment from the range of options available at any given point in time. The principle of informed choice thus contrasts with the narrower concept of informed consent, the latter implying only understanding of and agreement to a particular treatment.

Equality of Access

All women must be guaranteed full and equal access to medically insured reproductive health care, regardless of marital status, disability, race, sexual orientation, economic status, or residence in a rural or isolated region. It must be available in Canada's two official languages and resources must be devoted to improving the accessibility of health care to those persons in Canada who speak neither English nor French.

Equality is a much used, and abused, term. The meaning of equality, and in particular the legal meaning of sex equality, has been raised in many CACSW publications.[15] What must be emphasized here is that we are not arguing for abstractions. Sheilah L. Martin, author of the Council's publication,

Women's Reproductive Health, The Canadian Charter of Rights and Freedoms, and the Canada Health Act, states:

> Equality involves and requires a comparison within real life conditions. The focus is on the effects, consequences, and applications of a provision within its modern context. This is especially significant in relation to women's reproductive health where **equality requires not just notionally similar rights but the actual provision of services.** An equality analysis is consistent with international studies which indicate that the toll on the life and health of women caused by illegal abortion does not significantly decline unless abortion services made lawful in theory are made available in practice.
>
> Therefore, an equality analysis requires that attention be paid to the actual life circumstances of women and collectively based interests as well as personal autonomy.[16] (emphasis added)

Women's empowerment, bodily integrity, informed choice, and equality of access to reproductive health care can be enhanced or undermined by the development and implementation of the reproductive technologies now under review by the Royal Commission. As currently practised, these technologies have posed multiple dangers to the fundamental feminist principles listed above. Examples of such dangers include access restricted to "stable" heterosexual couples, lack of information on treatment alternatives, experimental uses of human reproductive tissues without the consent of the patient from whom the tissues originated, a general failure to distinguish between experimentation and treatment, and poor-quality counselling about adverse reactions to drugs administered in IVF and related technologies.

The CACSW strongly urges the Royal Commission to examine the clear and present dangers that NRTs present to women's health and well-being. We also hope the Commission's work will be guided by explicitly stated principles based on encouraging women's reproductive freedom.

GENERAL CONSIDERATIONS REGARDING WOMEN'S REPRODUCTIVE HEALTH AND WELL-BEING

The Royal Commission is mandated to inquire into the "implications of new reproductive technologies for women's reproductive health and well-being". The Commission's mandate is to focus on acute care and curative methods; accepted uncritically, the terms of reference could lead to a simple replication of the acute care/curative emphasis of the Canadian health-care system. It is by no means obvious that this perspective most benefits the reproductive health of people in Canada.

One of the negative implications of these technologies is their potential to deflect public, medical, and policy interest from the measures which would contribute most to women's reproductive health and well-being in our society.

Preventive Reproductive Health Care

Although many health policy analysts have pointed out that socio-economic factors play the largest role in popular health, preventive community health services and supports have been chronically underfunded. The general deficiencies in preventive community health are systemically institutionalized in reproductive health care. One example is perinatal mortality, the chief cause of which in Canada is the low birthweight of newborns due to maternal smoking and inadequate social support.[17] Teenage women experience higher than average rates of perinatal mortality. If health policy were designed to reduce perinatal mortality, it would result in provincial/territorial ministries of health following the lead of many European countries and adopting improved measures of social support for pregnant women, particularly those at socio-economic risk. The net benefits of increasing health expenditures on maternity support to pregnant women would be greater for perinatal mortality than would multiplying funds to prenatal screening and diagnostic services.[18]

A preventive approach to reproductive health care results in a critical approach to extremely costly, and sometimes ethically problematic, neonatal intensive care (NIC). Although poor nutrition and smoking are known to be contributing factors to prematurity, very few preventive measures have been taken. U.S. nurse-midwives working with women at socio-economic risk have had impressive results in reducing rates of prematurity, low birthweight, and perinatal mortality.[19] Unfortunately, the championing of NIC has been marked by a lack of attention to the need for resources to take preventive action against the known and preventable causes of prematurity.

For Aboriginal women, discussion of reproductive health care begins with concerns related to poverty, and lack of adequate housing and water supplies. It then proceeds to critiques of government inaction on native self-government and land claims, these being the prerequisites to securing the social and cultural structures which would support Aboriginal health and well-being.

The Aboriginal infant mortality rate is four times the rate found among non-Aboriginal people in Canada;[20] evidence also indicates a higher rate of premature births among Aboriginal women. The nutritional status of Aboriginal women is a contributing factor to obstetric problems, with anaemia being related to haemorrhages during the third stage of labour,[21] and childhood deficiencies in vitamin D intake related to pelvic deformities causing difficulties in labour.[22] These reproductive health problems are of such a high and preventable order that concerns associated with IVF or genetic transfer strike Aboriginal women as reflecting the rarefied interests of the socially affluent. It may also be the case that Aboriginal women have a wider range of social options for infertility than non-Aboriginal people in Canada. For example, the practice of custom adoption gives the woman/couple access to a stable relationship with a child, while birth parents still retain legal rights to the child. To those who have the social option of custom adoption, IVF and related technologies would likely make very little sense.

Proposals:

- that governments take steps to establish maternity benefit programs aimed at decreasing perinatal mortality;
- that midwifery practice be legally recognized and that community-based midwifery services be integrated into the health-care system.

Overmedicalization of Pregnancy and Childbirth

Sound evidence demonstrates a massive overmedicalization of reproductive health care. Once a particular practice has become routine in hospital obstetric care, research evidence questioning the practice seems to have little impact on medical behaviour. A few routine instances of overmedicalization are noted here for the purpose of illustration.

- Routine glucose tolerance testing for gestational diabetes produces results which are not reproducible in 50% to 70% of cases, and insulin treatment — the standard of care for positive results — has not been shown to improve neonatal outcome.[23] Unfortunately, glucose tolerance testing follows a general trend in screening tests; the landmark report of the World Health Organization, *Having a Baby in Europe*, estimates that — at most — 10% of prenatal screening tests have been evaluated by adequate trials.[24]
- Universal use of electronic fetal monitoring (EFM) during labour has not been shown to improve birth outcomes in low-risk pregnancies. However, it does lead to marked increases in the rates of Caesarean sections. EFM requires that a woman remain in the same position throughout labour. The routine use of EFM continues, despite current evidence indicating that regular auscultation (listening to sounds of hearts, lungs, etc.) is a more effective method with less iatrogenic risks.[25]
- The insistence on universal institutional confinement during childbirth is not based on evidence showing that hospitalization gives rise to better outcomes for women and newborn children.[26]
- The Canadian hysterectomy rate, twice that of Europe, is unnecessarily high.[27]

The situation of Aboriginal women is particularly acute. Aboriginal women have twice the level of obstetrical interventions found among non-Aboriginal women.[28] Federal and provincial/territorial policies authorize a 100% hospitalization rate for northern Aboriginal women during childbirth. Aboriginal women are evacuated from their communities for labour in hospitals sometimes far from their homes, leaving them separated from their families during and after birth.[29] The policy has social and emotional consequences: isolation, loneliness, and anxiety. Analogous regional accessibility problems occur within other communities in Canada, with women from the North Shore in Quebec sometimes travelling hundreds of miles to visit the only gynecologist in the region. Health-care resources spent on the evacuation of Aboriginal women from their communities would be better allocated to improving the socio-economic factors that increase maternal and perinatal risk, to creating birth centres on reservations, and to training community midwives (such training must reflect an emphasis on respect for birth practices and cultural traditions found among Aboriginal women).

Many more examples of the gross overmedicalization in Canadian reproductive health care could be given here.[30] We conclude with the simple point that the overmedicalization of pregnancy and childbirth represents a poor use of limited health-care resources. It also represents a system of reproductive health care at serious variance with research data. The net result is immense and unnecessary physical and emotional suffering by women, their children, and their partners.

This is the medical context in which the new reproductive technologies are being created.

Proposals:

- that a national inquiry be called to investigate Canadian medical practices for pregnancy and birth;
- that community-based reproductive health-care clinics be funded to provide an alternative to acute-care management of pregnancy and childbirth;

- that where/as advocated by Aboriginal women's groups, the policy of routine evacuation of Aboriginal women for childbirth to secondary- and tertiary-care hospitals be discontinued;
- that where/as advocated by Aboriginal women's groups, the federal government provide funding for birth centres in all Aboriginal communities and train community midwives to provide care during pregnancy and childbirth.

Misperception of the Fetus as Autonomous

A variety of innovations in photography, prenatal diagnosis, and medical treatments have led to the incorrect understanding of the fetus/implanted embryo as an autonomous life form with rights and claims of its own which can be weighed against those of the pregnant woman. Photographic images in the popular media commonly represent the fetus floating in a black void, that "void" being the woman in whose body the fetus resides and upon whom it is dependent for its existence.[31] Fetal surgery, IVF, and other conceptive technologies have assisted a cultural representation of the fetus as a patient separate from the maternal body.

These symbolic representations create the illusion that the fetus has a separate body and life from that of the pregnant woman, thereby setting the stage for the misperception of the pregnant woman and the fetus as having separate rights and potentially competing interests. A "conflicting interest" interpretation is found in *Crimes Against the Foetus*, a Law Reform Commission of Canada report which is centrally concerned with the protection of the fetus.[32] Therefore, it is essential to restate the obvious truth: **the fetus is located in and entirely dependent upon the body of a woman.** Any medical treatment of a fetus must occur through the body of a pregnant woman. Policy and ethical recommendations must place the pregnant woman in the context of her social relations as well as her economic and health concerns.

The growing tendency to decontextualize the fetus is illustrated by court-ordered obstetrical interventions, particularly forced Caesarean sections.[33] These court decisions violate the bodily integrity of the pregnant woman. Court-ordered fetal apprehension has authorized the surgical invasion of pregnant women's bodies and may be expanded to order lifestyle changes during pregnancy. Coerced medical treatment of women for the sake of the fetuses they bear demands that women give up control of their bodies in a way not often socially expected of human beings and never otherwise legislated.[34] The courts do not order the surgical removal of an organ or other tissues from a person's body against the will of that individual even in cases which would save the life of a second party. The Canadian legislative system also protects men and non-pregnant women from being forced against their will to submit to medical procedures which might save the life of a living child or relative. Court-ordered fetal apprehension is a violation of the principle of bodily integrity.

The above discussion of preventive reproductive health care, the overmedicalization of pregnancy and childbirth, and misperceptions of fetal autonomy are but a few of the most pressing concerns related to women's reproductive health. These concerns cannot be disconnected from the realities of daily life for many women: inadequate maternal and parental supports, poverty, insufficient child-care facilities, and the underrepresentation of women which results in the underrepresentation of their priorities in the decision-making structures of Canadian society. The new reproductive technologies should not be developed at the expense of attention to these problems and the allocation of financial and human resources to meet women's needs.

In the context of the work of the Royal Commission, the CACSW would like to reiterate the reproductive health principles it adopted in March 1988:

1. Reproductive choice is an equality issue. In our society, women become pregnant, bear and raise children under conditions of inequality. Partial remedies for these inequities include: increased child care facilities; economic self-sufficiency for women; research to develop safe methods of contraception; access to a full range of reproductive health services; development of information, resources and services to support family planning and birth control; sex education; and access to abortion.
2. A pregnant woman has the right to determine the best medical treatment for herself or the fetus she is carrying, in consultation with advisors of her choice and without threat of third party intervention or obstruction. No woman should be penalized for making a decision which she believes furthers her physical and mental health, the health of her children, the health of her family as a whole, or the health of any fetus she is carrying.
3. A pregnant woman who has made the decision to have an abortion should have access to abortion services at the earliest opportunity, and should not be forced into a late term abortion or denied access altogether by reason of obstructive diagnostic procedures and practices, financial impediments, geographic location or legal and quasi-legal proceedings. Reproductive health services and abortion must be available to women equitably throughout Canada, and be funded completely by provincial health insurance plans, in keeping with the principles of universality, accessibility and comprehensiveness as stated in the Canada Health Act.

INFERTILITY SERVICES AND RATIONAL HEALTH POLICY

Health Policy

Normal fertility, subfertility, and infertility have been understudied. Data on male infertility is particularly sparse. Basic epidemiological research is needed to form a realistic estimate of the Canadian infertility rate and the etiology of infertility. These studies are the prerequisite to informed discussion for health-care policy and will assist in making accurate projections of what demands, for what services, subfertile and infertile people are likely to place on health-care systems.

In Canada, the infertility rate is defined as the percentage of couples who fail to conceive a viable fetus after one year of unprotected intercourse. Estimates place the infertility rate at 15% for couples, and slightly less than 7% for women in Canada.[35] These figures do not distinguish between sterility and subfertilty; considerable numbers of women in couples are able to conceive without medical assistance after one year. The World Health Organization defines infertility as failure to conceive a viable fetus after two years of unprotected intercourse; on the basis of the WHO definition, the estimated infertility rate in developed countries falls to 10%.[36] The spontaneous "cure" rates between one and two years indicate that setting the infertility rate at one year inflates the estimate without clear cause, exposes subfertile individuals to unnecessary treatments and the risks these may entail, and leads to an avoidable drain on health-care budgets. It also creates unnecessary and harmful psychological worry for women (and men) trying to become parents.

From the perspective of service provision and research, IVF and related technologies are expensive. These technologies are resulting in debate about optimal distribution of health-care resources. In 1987, 40% of health-care financing in Canada was spent on hospitals, as opposed to an estimated 4% on public health.[37] Our public health-care system has been chronically underfunded, and NRTs could further aggravate the disproportionate allocation of funds towards hospital-based care. The following general questions must be raised: What proportion of our health-care funding should be directed to infertility services? Within infertility services, how should money be distributed between the public health system and hospital-based services? The CACSW believes health-care budgets should reflect a primary commitment to the prevention of infertility through the public health system, a suggestion consistent with the Health Promotion Framework announced by Health and Welfare Canada.[38]

Infertility services have four components: prevention, social options (adoption, custom adoption, fostering, voluntary childlessness), standard medical and surgical options, and new conceptive technologies. Each of these components has two aspects: research and services. The cost of IVF and related conceptive technologies may lead to disproportionate expenditures in this field at the expense of financing other infertility options. This potential may be

illustrated by 1988 spending: "Canadian government funding agencies spent $3.5 million on basic NRT research, [while] only slightly over $400,000 was spent on public health and health service research activities related to reproductive disorders."[39]

IVF is costly:

> From 1985 to the end of 1988 fiscal year, Ontario spent over $7 million in direct funding to IVF clinics. Six million dollars went directly for clinic services while another $1 million was laid out on startup grants and equipment costs . . . Of 1,500 to 1,800 couples who underwent IVF to the end of 1987 only 207 babies were born to 130 couples . . . cost per baby was $35,000.[40]

Because some treatments resulted in multiple births, cost per woman/couple was closer to $55,000, not including neonatal care. When Ontario expenditures on IVF clinics between 1985 and 1988 ($7 million) are compared with the total public health funding for reproductive health disorders by the federal government for 1988 ($400,000), one can begin to form an idea of the serious challenge IVF and related technologies represent to rational health planning in infertility services.

IVF and related technologies should be limited to women whose medical indications (special symptoms that point out a suitable remedy or treatment or show the presence of a disease) show the most promise of benefiting from the procedures. Women are currently undergoing IVF for many medical indications where scientific evidence has not demonstrated the superiority of this procedure over more standard medical options such as hormonal treatments and microsurgery. For reasons of efficacy, safety and cost-effectiveness, medical indications for IVF and other conceptive technologies should be interpreted narrowly. The CACSW also urges that the numbers of cycles be limited to a maximum of four because the probability of success in IVF drops sharply after three to four ovulation cycles.

Proposals:

- that the federal government fund basic epidemiological research on normal fertility, subfertility, and infertility to determine incidence and cause differentiated by gender;
- that infertility be defined, for heterosexual couples, as the inability to conceive a viable pregnancy after two years of unprotected intercourse;
- that the Commission, in recognition of the fact that current definitions of infertility presuppose male-female couples, consult with lesbian and single women to adopt a definition of infertility appropriate to their circumstances;
- that health ministries in all jurisdictions, together with medical associations, limit the medical indications for IVF and related conceptive technologies;
- that IVF and related procedures be limited to a maximum of four ovulation induction cycles.

Prevention of Infertility

Infertility prevention research and services have not received adequate funding. Because infertility has many causes (including contraceptive history, sexually transmitted diseases, age, and occupational health hazards), risk factors for infertility urgently require more research. Health-care resources should be directed as much toward the prevention of infertility as to medical options for new conceptive technologies.

Proposal:

- that governments, in each fiscal year, not spend more on IVF and related technologies than on public health research and services for the prevention of infertility.

■ Contraceptive History

Intrauterine devices (IUDs) have a possible linkage with pelvic inflammatory disease (PID), a common risk factor for infertility in women. PID is not a federally reportable disease.

Safety and effectiveness in contraception tend to vary inversely, indicating the need for research on safe **and** effective contraceptive methods. Barrier methods of contraception provide protection against sexually transmitted diseases and the consequent risk of infertility. Hormonal contraception does not have this added benefit.[41]

Proposals:

- that the manufacturers of contraceptive drugs and devices be required to indicate the following clearly on the packaging: failure rates, secondary effects, and the expiry date of their products;
- that pelvic inflammatory disease be classified as a federally reportable disease;
- that the federal government fund research on intrauterine devices as a risk factor for infertility;
- that the federal government give high priority to funding research into male and female contraception which is both safe and effective, with safety interpreted to include the prevention of infertility.

■ Sexually Transmitted Diseases

Sexually transmitted diseases constitute a prime preventable cause of infertility. Currently, neisseria gonorrhoea and chlamydia trachomatis are the two main sexually transmitted diseases in Canada which result in infertility, particularly in young women.[42] In fact, the incidence of these diseases is likely underestimated due to asymptomatic conditions in some women and physician failure to report.[43] Chlamydia has only been federally reportable since the beginning of 1990; some provinces have yet to enact the legislation which would

add chlamydia to the list of reportable diseases. Sexually transmitted diseases, especially gonorrhoea and chlamydia, put women at greater risk for PID and ectopic pregnancy, both of which increase the risk of infertility. A 1990 national study revealed the dramatically high incidence of STDs among young women; "women between 15 and 19 have the highest rate of gonorrhea of all age- and sex-specific groups in the country . . . 73 per cent of all chlamydial infections are found in the same group".[44] These figures clearly illustrate that young women are engaging in unprotected intercourse (i.e., "unsafe sex") which has important consequences for the spread of HIV, the virus associated with AIDS. Ironically, widespread use of condoms (a low-technology solution to the problem of contraception) would dramatically prevent both infertility and STD/HIV transmission.

Sex education is greatly needed in schools and for a public education program, including information on the fertility risks associated with STDs. Programs must be devised and their effectiveness evaluated.

Proposals:

- that governments support public education and school programs on family planning, sex education, contraception, and sexually transmitted diseases, and that periodic evaluation of such programs be carried out by qualified personnel;
- that provincial/territorial medical associations, in cooperation with health ministries, encourage physicians to be more consistent in recording instances of reportable STDs to produce a more accurate assessment of their incidence.

■ Occupational Hazards to Reproductive Health

Numerous hazards to the reproductive health of workers have been proven to exist and are presently regulated: DBCP, lead, and vinyl chloride, among others. Discussion of chemical hazards is complicated by the fact that few chemical products used in workplaces actually have been examined and classified by the Canadian and U.S. federal agencies responsible for authorizing

their release.[45] This means that the safety of most chemical products in Canadian workplaces has not been assessed and that, therefore, the reproductive health hazards of most chemical products with which workers in Canada come into contact is unknown. This is a mass-scale gamble with the fertility and other forms of reproductive health of workers across Canada.

Ionizing radiation is a physical hazard, and its minimum safety levels for reproductive health have been the subject of prolonged and ongoing social and scientific debate. Exposure to occupational biological hazards has been less well publicized than chemical or physical hazards, but workers in many occupations face reproductive dangers of coming into contact with cytomegalovirus, hepatitis, rubella, chicken pox (varicella), and tuberculosis.[46]

Business people, public health officials, and legislators primarily have targeted pregnant women or women of reproductive age for protection against reproductive hazards, frequently recommending the exclusion of these subgroups of women from occupations or tasks which would jeopardize them or fetal development. Resulting standards have discriminated against women in the workplace and also have jeopardized male reproductive health.

Proposals:

- that the federal government amend the Canada Labour Code to prevent discrimination in hiring, job placement, promotion, and other conditions of employment based on factors related to reproductive physiology, such as reproductive capacity, pregnancy, or childbirth;
- that the Canadian Centre for Occupational Health and Safety establish a statistical database recording the type and degree of exposure to reproductive hazards in Canada and an estimation of the worker population at risk for each identified hazard;
- that the federal government make greater efforts to increase federal/provincial/territorial consultation and information-sharing and, through such efforts, attempt to establish a uniform high level of standards in occupational health and safety;
- that standards setting out permissible levels of exposure to workplace hazards should:

a) establish a single standard for each hazard which would ensure maximum protection for the most susceptible worker of any age and either sex;
b) ensure that laboratory or other testing of all new substances or processes include screening for teratogenicity, mutagenicity, carcinogenicity, and evidence of effects on lactation before introducing them into the workplace;
c) be measurable, understandable, and capable of general enforcement;
d) be re-examined on a regular basis;

- that the federal government ensure that research into all aspects of occupational health hazards affecting reproductive physiology be stimulated by

a) specifically allocating increased budgetary and staff resources for this purpose to any federal department/agency/responsibility centre involved in occupational health and safety issues;
b) specifying that where federal money to carry out occupational health studies on humans is granted to any research body or individual, the research design and the results must include both female and male workers when both sexes are employed in the particular workplace;
c) designating research money to be used in studies of employment sectors with a high proportion of female workers.

Counselling Services

High-quality counselling services should be provided for women and men who are infertile/subfertile. Women and men need to be informed of the various social and medical options available and given honest guidance about the safety and effectiveness of medical options. Contact with mutual aid organizations should be encouraged in infertility counselling.

Because the "couple" may not agree on ranking options, mediation of differences must be part of the counselling work. Many women classed as infertile are subjected to enormous pressure to undergo any and all forms of infertility treatment regardless of personal safety. In these situations, counselling would support women through difficult processes of decision-making with respect to their own bodies. For these reasons, the CACSW concurs with the World Health Organization's position that infertility counselling should be

institutionally separate from medical and social infertility programs. Such independence would protect informed choice for women.

Proposals:

- that governments fund infertility counselling services;
- that infertility counselling services "be independent of social and medical programmes for the management of infertility. Funding for these services should not come from clinics or industry."[47]

FEDERAL GOVERNMENT RESPONSIBILITIES FOR REPRODUCTIVE HEALTH PROMOTION AND PROTECTION

Standardization and Collection of Information

The lack of a federal regulatory or informational presence in NRTs is all the more serious because of the paucity of provincial/territorial and professional standards guiding research and monitoring. Reliable Canadian information on infertility and NRTs is scarce because of the lack of systematic data collection about research, services, and clinical treatment; known causes of infertility such as PID and chlamydia are either not federally reportable or are underreported. At the very minimum, the federal government has a significant responsibility to provide information on health protection and promotion as these relate to infertility and NRTs.

Proposals:

- that a national system of standardized, mandatory reporting for infertility and NRTs be developed to include data on research, services, techniques, and treatments;
- that a national patient and treatment register for IVF and related conceptive technologies be established, as set out in the recommendation in the section "Evaluation: Access and Cost".

Standards of Evaluation

The CACSW is not confident that NRTs are receiving adequate testing to evaluate their safety and efficacy before routine clinical use (see sections "Evaluation: Efficacy" and "Evaluation: Safety"). Some groups have called for randomized controlled trials in response to inadequate evaluation of NRTs, and as a result of concern with women's reproductive safety and that of their children. These trials have ethical and operational problems and, though desirable in some circumstances, should not be regarded as the sole standard of objectivity.[48] For example, the kind of randomized trials used by pharmaceutical manufacturers seeking Canadian licensing do not detect long-term adverse reactions to drugs, nor are they particularly effective in discovering rare adverse reactions (the total population investigated tends to range from 500 to 2,000 people only).

The application of new statistical methods such as Bayesian statistics and multivariate analysis may in future decrease reliance on randomized clinical trials.[49] Moreover, standardized, mandatory reporting for IVF and related technologies and the creation of a national patient and treatment register for IVF would establish an epidemiological database for cohort studies, a more powerful research method than case-control studies. Better evaluation of NRTs is a necessity for women's reproductive health, but it may be advisable to develop a plurality of research instruments and methods.

Proposal:

- that government funding be made available to encourage biostatistical research on appropriate research methods for evaluating NRTs.

The System of Ethics Review

New ethical criteria must be formulated to govern investigation into emerging fields of scientific research. NRTs put the limitations of the Canadian system for devising and implementing bioethical principles into sharp relief. Canadian biomedical ethics boards and councils are generally male-dominated, medically controlled, and restricted in social composition. The guidelines of the Medical Research Council (MRC) call for community representation on local research ethics boards, noting that, "Lay members affiliated with a hospital or university board are often suitable, but the board should ideally include non-affiliated individuals. Community bodies may assist in the selection of such members."[50] The concept of "community" is left exceedingly vague, although the MRC is much more precise regarding the "relevant specialists" and "other disciplines" which would contribute to research ethics boards: "a clinical psychologist or other mental health expert", scientists, nurses, bioethicists, philosophers, theologians and lawyers.[51] A 1989 survey of research ethics boards showed that 39 of 53 respondents did include lay membership, but with the meaning of community narrowly interpreted.[52] Of the 39 boards having community members, "several of them are affiliated with the institution, for example, as patient representatives or as a member of the board of governors of the hospital. Many institutions did not specify a method of selection of lay members . . . A few select from among the hospital or from community service clubs such as the Junior Chamber of Commerce."[53] Community members are thus drawn from a restricted social stratum, with demonstrably little institutional interest in seeking out representatives from, by way of example, immigrant women's groups, injured workers, or racial minorities.

The Royal College of Physicians and Surgeons of Canada has established the National Council on Bioethics in Human Research, and although the CACSW welcomes this initiative, the composition of the National Council suffers from the same limitations as the research ethics boards. Of 15 members (plus one ex-officio member), four places are reserved for the "public", interpreted as "a philosopher/theologian, a lawyer and two community members".[54] Although the CACSW appreciates the important and hard work contributed by individual boards and the National Council, it must be admitted that the process of social

recruitment to these groups is highly selective and that a broader and more generous understanding of "community" and "the public" is warranted.

Ethical issues raised by NRTs are many and complex: accessibility, informed choice, the empowerment of women, and bodily integrity. Under the current underdeveloped conditions, genuine community participation in planning and overseeing NRTs is required; the selection of community representatives should not be in the hands of NRT service providers. The CACSW agrees with the World Health Organization, which advises that committees overseeing service systems for infertility should consist of a group of informed lay people from the community, at least 50% of whom should be women.[55] The proceedings and deliberations of these committees should be available to the public. Although the WHO directive was intended to apply only to infertility services, the CACSW believes the committees should be mandated to oversee all aspects of reproductive health services. The local reproductive health committees would relieve research ethics boards of their powers of ethical review over reproductive health concerns.

The current system of ethical review is constructed narrowly to apply only to research and not to the planning and monitoring of services. The National Council on Bioethics in Human Research will prove of great help in devising ethical criteria for NRT research, yet it is not clear that the ethics of service provision fall within its purview. In any case, the National Council works under terms of reference restricting it to consultative, informational, and consensus-building activities. Moreover, a tension exists between national level ethics committees and local, independent research ethics boards. According to MRC guidelines, "the institution within which the researcher works has the major responsibility to ensure that the research meets the ethical standards of society".[56] The MRC is dependent on local research ethics boards because grant applications to this federal agency are not subject to full ethics review: "The applications, which are written primarily to address scientific issues, and which are limited in length, cannot fully address specific questions of ethics, and are not ideally suited to ethics review."[57] Therefore, the local boards and the MRC are in a formal position of co-dependency with respect to ethics

reviews of MRC grant applications, with research ethics boards being a weak partner.

The Law Reform Commission of Canada has offered a sobering evaluation of local ethics review practice: "In effect, in most cases these committees now do nothing more than accept or reject protocols. Once they approve an experiment because they consider it ethical, they have no authority to monitor it."[58] Under these conditions, it is not surprising that the MRC's *Guidelines on Research Involving Human Subjects* recommends that research boards be monitored by the MRC.[59] The system of ethics reviews thus has no clear articulation of authority between national and local levels; moreover, the local research ethics boards have multiple problems in terms of their effective control on experimentation and their social composition. For these reasons, the CACSW opposes MRC recommendations for embryo research which suggest that "the local REB (research ethics board) is an appropriate forum in which to access each protocol".[60] The purported sensitivity to local ethical standards which motivates the MRC guidelines would lead to a variety of conflicting standards for embryo research and genetic engineering, resulting in potentially grave damage to the human gene pool. Uniform, national standards for embryo research are needed.

Thus, Canada needs a national body to review and approve research proposals, set ethical standards, set national standards of informed consent for NRT research and therapy, standardize data collection on NRTs, and monitor access and service provision. The body should have broad representation from the lay community and the public; as well, at least 50% of its members should be women. Its decisions and deliberations should be accessible to the public.

Proposals:

- that local reproductive health committees be formed in all health facilities where research and treatments affecting human reproduction take place. Members of reproductive health committees should be chosen independently of service providers, and should consist of at least 50% women. The mandate of the reproductive health committees would include ethical reviews of research, the ethics of service provision, and the planning and monitoring of reproductive health services in their institutions;
- that a national body be established to review and approve research proposals, set ethical standards, set national standards of informed consent for NRT research and therapy, standardize data collection on NRTs, and monitor service access and provision.

Monitoring Reproductive Pharmaceuticals

Canadian laws and regulations governing prescription pharmaceuticals and devices do not sufficiently protect women's reproductive health. Ironically, the internal standards of the pharmaceutical industry serve as the major source of public protection; higher standards of risk analysis for drugs followed the thalidomide disaster and were linked to the incentive of lowering the insurance costs of pharmaceutical companies.[61]

Drugs are monitored by the Health Protection Branch (HPB) of Health and Welfare Canada.[62] The Bureau of Human Prescription Drugs in the Drugs Directorate of the Health Protection Branch oversees the process of approving new reproductive drugs. Each manufacturer is required to make a "pre-clinical new drug submission" before conducting tests on human subjects. If clinical studies demonstrate its effectiveness, the manufacturer then submits a "new drug submission" which supplies extensive albeit confidential information on the drug in question. If this second submission is approved, the Bureau issues a notice of compliance which allows the manufacturer to market the drug.

During the period a product is still termed a new drug, manufacturers must monitor and report adverse or unusual reactions which occur within Canada.[63] These reports must be made within 15 days of receiving information on such reactions; failure to do so can result in the cancellation of the notice of compliance. After the HPB has dropped a drug from its classification as new, the manufacturer is no longer required to report on unusual occurrences. When the Health Protection Branch becomes aware of an alleged adverse reaction to any drug, old or new, it has the power to authorize that the manufacturer prove its safety within 90 days. Over the past generation, these factors have led to the practice of pharmaceuticals remaining classified as new on a virtually indefinite basis — a beneficial bureaucratic adaptation to a poorly designed regulatory system.

The public does not have access to information in the pre-clinical submission or the new drug submission. According to HPB policy, the public first receives official word of a new drug when the notice of compliance is issued. Furthermore, there is no structured place at any point in the process for public intervention. Although a separate drug adverse reaction program does exist, reporting occurs on a purely voluntary and ill-used basis.

Dr. Joel Lexchin, in his study of the regulation of pharmaceuticals by the Health Protection Branch, has noted of DES:

> In 1971, after the HPB learned that DES could cause cancer in the daughters of women who had taken the drug, its only action was to withdraw approval for DES to be used to prevent threatened miscarriages. Between 1971 and 1983 the HPB issued only one press release about the matter to the general public.[64]

Doctors may prescribe drugs for uses other than those approved by the HPB, and they are under no formal obligation to tell the patient that the treatment has not been approved.

HPB pharmaceutical control and regulation is inadequate for monitoring the pharmaceuticals currently used in IVF and related conceptive technologies. The complete lack of public participation in monitoring and the secrecy

of information pose risks to women's reproductive health. The postmarketing followup of drug adverse reactions is particularly weak. The CACSW recommends a general restructuring of the procedures used for approving and monitoring pharmaceuticals at the Bureau of Human Prescription Drugs.

Proposals:

- that the Bureau of Human Prescription Drugs give public notice of all pre-clinical drug submissions and new drug submissions;
- that the public have access to all information in pre-clinical drug submissions and new drug submissions;
- that physicians be required by law to obtain the informed consent of patients in cases where a pharmaceutical is being prescribed in a way not approved by the Health Protection Branch;
- that increased funding be provided to the drug adverse reaction program to expand its staff and to publicize among physicians the importance of reporting drug adverse reactions.

Women's Reproductive Health Centres

Women's reproductive health care needs and experiences vary according to factors such as marital status, disability, race, age, sexual orientation, economic status, place of residence, and Aboriginal heritage. An extensive albeit informal network of women's groups has developed to articulate the common ground as well as the distinct needs of women throughout Canada. These groups have identified and studied problems affecting women, and have initiated projects and developed policies addressing women's needs. For example, family violence is now identified as a government priority, but it was women's groups who first recognized and sought to alleviate the needs of battered women.

Women's organizations have suffered drastic cuts in the funding for their advocacy, education, research, and publications. *Healthsharing* magazine, which has been an important vehicle for sharing information and perspectives on health issues for women, including NRTs, was but one target of these cuts.

Women's groups are under constant pressure of being slowly, but steadily silenced. The federal government must fully restore funding to women's groups (doing advocacy, education, research, and publishing) if women are to participate in the discussions and debates during and following the work of the Royal Commission.

The Commission marks the first stage in concerted Canadian public discussion of the transformations taking place in human reproduction. It is essential to continue this impetus and build a strong institutional place outside the medical community for all women to develop knowledge of these issues. Thus, the CACSW calls for a network of women's reproductive health centres to identify needs, develop policy, and distribute information about NRTs and reproductive health issues.

Proposals:

- that the federal government fully reinstate funding for the advocacy, education, research, and publication functions of women's groups;
- that the federal government support an independent, organized voice for women's health protection and promotion in reproductive health care by funding a network of women's reproductive health centres across Canada.

REPRODUCTIVE TECHNOLOGIES

In Canada today, the development of IVF and related technologies can most charitably be described as anarchic.

Provincial/territorial and federal levels of government have exercised little control or regulation concerning NRT practice and research. The medical profession and governments have done little in the way of formulating standards for the testing and monitoring of NRTs, thereby facilitating the confusion between research and treatment that marks NRTs.

The lack of standardized reporting and record-keeping hamper public and medical access to information regarding techniques, success rates, location of clinics, and pharmaceutical use. Problems of access to information are compounded by commercial secrecy which make it extremely difficult to document the role of business in NRT research and services. The anarchic pattern in NRT research unfortunately echoes past performance in obstetrics and gynecology: poor evaluation of techniques and drugs, and routine clinical practices contraindicated by scientific evidence.

The social implications of prenatal genetic screening differ markedly from in vitro fertilization/embryo transfer (IVF/ET); generally speaking, reproductive technologies have no uniformity of medical and social effect, and they should be evaluated separately. Overall, however, one sees recurrent problems of informed choice, informed consent, and the quality of counselling for women. Far higher ethical standards and greater clarity of ethical criteria will be required for research and practice if NRTs are to benefit women's reproductive health.

IVF/ET and Related Conceptive Technologies

IVF/ET and related procedures such as GIFT (gamete intrafallopian transfer) are technologies which have not been properly evaluated in terms of efficacy, safety, and cost. Policy-making has lagged behind research on IVF, delaying critical debate on health-care priorities. Thus, in Ontario, millions of dollars have been spent on IVF clinics, but the Ontario Ministry of Health has no policy on the role of IVF in the provincial health insurance system. This constitutes practice without policy.

The benefits of IVF should be carefully weighed against its financial costs within the system of infertility research and services as a whole. The CACSW believes that IVF should be classed as experimental and subjected to the high standards of informed choice and consent outlined in the Nuremberg Code and the Helsinki Declaration (international agreements on medical ethics and human experimentation).

Proposal:

- that IVF be classed as experimental, funded through research budgets, and subject to the high standards of informed choice and consent outlined in the Nuremberg Code and the Helsinki Declaration.

■ Evaluation: Efficacy

IVF/ET has low efficacy rates with a wide range of variation across clinics. Efficacy rates are reported in ways which women health consumers not versed in the medical literature find difficult to interpret. Success may be computed in biochemical, clinical, or live-birth pregnancy, only the last of which is relevant to women consumers. Quoted figures may exclude those women from whom eggs were not recovered despite ovulation stimulation. The practice of subsetting, giving only the success rate for treatment of one type of infertility, has been reported. These are all techniques for inflating efficacy rates in a context of competition among clinics. In consumer terms, they are equivalent to false advertising and they violate the public interest.

Currently, clinics are not required to be licensed, although proposals to this effect have been made. National standards for the accreditation of clinics, certification of practitioners, and monitoring of clinics are advisable, particularly in light of proliferating private IVF clinics.

IVF was first developed as a treatment for bilateral occlusion of the fallopian tubes and is still most effective as a means of dealing with this form of infertility. It is less effective for severe endometriosis, PID, or idiopathic infertility. In addition, IVF is used as a treatment for male factors such as low sperm count. Given the safety risks involved in this procedure, as well as high neonatal costs, the indications should be limited to exclude, at least, male factors and idiopathic infertility. In the case of male factors, alternative fertilization should be the preferred technique.

Because randomized control trials or other biostatistical methods have not been used, IVF cannot be compared with conventional forms of treatment for the subclasses of infertility. This research gap hampers informed choice among treatments for those women whose infertility does not originate in bilateral tubal occlusion. Until these studies have been done, the desirability of IVF over other options is debatable. Disclosure of this research gap to infertile women should be considered a necessary condition for informed choice among treatment alternatives.

The CACSW notes that, as the quote below demonstrates, IVF is not the "last chance" for the infertile:

> Studies of women accepted for IVF/ET programmes show that 7-28% conceive naturally before receiving treatment or within two years after discontinuation. When women with bilateral tubal occlusion are excluded, treatment-independent pregnancy rates of 12% and 25% have been noted.[65]

A recent Canadian study has further shown that women and men in IVF programs may sometimes be suffering from secondary infertility, i.e., experiencing fertility problems despite having had a child or children by a previous or current relationship.[66]

Proposals:

- that research be commissioned to compare efficacy rates in the various subclasses of infertility for women who have undergone IVF/ET and groups consisting of nontreated women as well as women receiving more standard forms of therapy;
- that, for reasons of safety, efficacy, and cost, the indications for IVF/ET be restricted to those with the best success rates and that male factors not be considered an indication for this procedure;
- that a national, compulsory standard of reporting IVF/ET and GIFT success rates to health consumers based on live births per 100 stimulation cycles be adopted. Information on efficacy rates should be reportable and mandatory. Summary statistics should be made available to the public;
- that standards of personnel and practice for IVF clinics be established, and that clinic licensing be made mandatory.

■ **Evaluation: Safety**

IVF poses risks to the health and safety of women and babies:

> The ovarian hyperstimulation syndrome occurs in 1-2% of women treated with ovulation inducing drugs. Multiple gestation occurs in approximately 25% of IVF pregnancies. The perinatal mortality rate for IVF babies is four times and the neonatal mortality rate twice that of the general population. The rate of very low birth weight among IVF babies is over 11 times higher than in the general population.[67]

Low birthweight is associated with neurological and sensory disability. Women also face higher complication rates in pregnancy and higher rates of Caesarean section.

The short- and long-term adverse reaction to drugs, singly and in combination, which are used in IVF/GIFT are not well known. Current research links clomiphene citrate with cancer,[68] auto-immune disease,[69] ectopic/heterotopic pregnancy,[70] neural tube defects,[71] and chromosomal abnormalities in IVF ova.[72] Thus, it is not surprising that the entry for this drug in the *Compendium of Pharmaceuticals and Specialties* cautions that "clomiphene citrate is a drug of considerable risk".[73] Because adverse reactions may appear inter-generationally, a patient registry is needed to do long-term followup on children born to women treated with IVF/ET and GIFT. Superovulation of women for the sole purpose of egg donation should be prohibited due to safety risks.

Women and men in IVF/ET need counselling before, during, and after procedures. Improved and nondirective counselling methods need to be fashioned based on high standards of informed choice and consent. Counselling services should be institutionally separated from IVF and GIFT clinics to provide independence of perspective and to maximize informed choice among the infertile and subfertile. IVF and GIFT clinics should be institutionally responsible solely for counselling related to informed consent for their services.

Proposal:

- that a national IVF/GIFT patient and treatment register be established, with mandatory reporting by all IVF/GIFT clinics of complications and interventions during pregnancy and childbirth, perinatal and neonatal mortality and morbidity, and pharmaceutical use.

■ Evaluation: Access and Cost

Access to IVF and GIFT generally has been confined to male-female couples in "stable relationships". These procedures should not be accessible only to the socially and economically privileged. The CACSW believes that women should be guaranteed access to NRTs without discrimination based upon their marital status, sexual orientation, disability, race, or socio-economic status.

IVF is very expensive. In Ontario, as mentioned above, expenditures have averaged $35,000 per baby or, factoring for multiple births, $55,000 per couple.[74] IVF is associated with higher than average treatment costs during pregnancy, childbirth, and neonatal care.

Although IVF/GIFT can help some infertile women bear children, people in Canada must remain aware of other areas of reproductive health care worthy of compassionate financing, such as nutritional programs and occupational health and safety. Setting health-care priorities in the financing of infertility services raises very hard issues and choices. The CACSW believes that the proposal to restrict the medical indications for IVF to those women who have the strongest chance of benefiting from it and from no other options best guarantees justice to infertile women, the safety of women, and balanced priorities for our health-care system.

Proposals:

- that women be guaranteed access to NRTs without discrimination based upon marital status, sexual orientation, disability, race, or socio-economic status;
- that access to IVF/ET and GIFT be restricted to those women whose medical indications show the greatest likelihood of success and who clearly would not benefit from other forms of infertility services.

Genetic Engineering and Embryo Research

Of all the fields being investigated by the Royal Commission on New Reproductive Technologies, genetic engineering has the greatest potential for both benefit and harm to humanity. Genetic therapy on embryos, fetuses, and adults with serious genetic defects (such as cystic fibrosis or Tay-Sachs Disease) would be of great good to humanity and particularly to women in our capacity as primary caregivers on a global level. The darker side of genetic engineering is its potential to damage the human gene pool and to link with eugenic ideology and practice on a more powerful scale than has been possible previously. The formulation of social and ethical criteria to guide genetic engineering raises multiple, complex issues. Because of the lack of feminist commentary in this area, the CACSW emphasizes the preliminary character of these observations.

Existing literature draws a sharp distinction between somatic gene therapy and germ-line therapy on the grounds that the former is a treatment type affecting solely individuals with genetic defects, while the latter will result in the inheritance of medical interventions to the human genome, the net genetic constitution of each individual. The repairing of human germ-line cells would enter the gene pool, potentially not being expressed for generations and multiplying exponentially. As well, germ-line therapy might be used not only to correct for serious genetic defects but also to "improve" the performance of athletes or to breed workers resistant to occupational health hazards, possibly with patenting of procedures or embryos. Current ethical research

guidelines for experimental research on human subjects may be sufficient to cover the development of somatic cell genetic therapies; however, more stringent guidelines for germ-line research and therapy must be formulated.

In the light of recent discussion in philosophical ethics, the CACSW suggests that the human gene pool be regarded as the collective property of humanity.[75] Because of the enormous risks that germ-line gene research and therapy pose to the human gene pool, and the current lack of socio-ethical standards in this field, local research ethics boards should not have the authority to approve germ-line genetic research. The CACSW does not believe that the system of locally controlled, volunteer-based research ethics committees will provide an adequate framework for protecting the public interest in monitoring genetic engineering and embryo research. The safeguarding of the human gene pool should be considered a matter of federal jurisdiction in health protection. The proposed national body, discussed in "The System of Ethics Review" section, should have ultimate approval of germ-line genetic research and embryo research which might modify the gene pool.

The Medical Research Council should not be the primary or ultimate forum for decision-making in germ-line gene transfers, because the development of genetic engineering should not be controlled solely by the advice of medical doctors and research scientists. Scientists *qua* scientists have limited interest in placing extrascientifically-derived barriers to their capacity for research. Moreover, as discussed in "The System of Ethics Review" section, medical interests dominate research ethics boards, the Medical Research Council, and the National Council on Bioethics in Human Research. They construe public participation in their deliberations as the limited inclusion of representatives from professional elites. If the human gene pool is understood as the collective property of humanity, then control of interventions in it and the judgement of risk and benefit are a public matter and need the participation of people who are not medical doctors, research scientists, lawyers, or statisticians. In addition to the need for representation by medical interests on the national ethics board, the CACSW strongly recommends the inclusion of women's and labour group representatives, community health activists, and other lay people.

A distinction should be made between the correction of genetic defects and alterations for what might be argued as genetic "improvement". The second type of genetic manipulation should be declared unethical, since it could easily end in the creation of genetically-based social stratification. Experimentation with human cloning and the creation of transgenic, human-animal hybrids also should be prohibited on the ground that these experiments would result in the purposeful constitution of social elites and sub-human social strata, a situation which would interact in complex ways with socio-economic factors.

The social risks in creating human clones and transgenic hybrids far exceed potential individual or social benefits from the existence of such life forms. Forms of human recombinant-DNA, genetic therapies, and humans born from these techniques should not be subject to patent protection. They violate the principle of the human gene pool as the collective property of humanity, and border on the internationally prohibited practice of buying and selling human beings.

Additional social problems associated with genetic engineering may be foreseen with occupational genetic screening. Some would argue that this practice may be justified where such screening aims at discovering workers who might be highly susceptible to genetic damage from working conditions to which the vast majority of the population would not react negatively. However, if the intent is to isolate small numbers of male and female workers highly resistant to workplaces filled with genetic hazards, in so doing excluding otherwise healthy workers, the practice would become perniciously linked to the toleration of workplaces dangerous to health needs.

Genetic engineering research will in part require access to eggs and embryos obtained through invasive procedures on women's bodies. Risks to women arise from stimulation to produce more eggs than are intended for reimplantation after fertilization; the "spare" eggs and embryos may then be used for research, potentially without patient consent. A related problem now occurs in IVF procedures, where more embryos may be formed than are later implanted in the woman from whom the original ova have been removed; the

"excess" embryos may be the by-product of attempts to ensure an adequate number of healthy embryos for implantation as distinct from research.

The above-mentioned situations raise two sets of issues: informed consent, and the control/disposal of reproductive tissues. Without her explicitly informed consent, no woman should be exposed for the purposes of research to higher doses of drugs or lengthier invasive surgery than would be necessary for her own treatment. This principle, linked to the fundamental principle of bodily integrity, amounts to no more than a reaffirmation of the high standards of consent needed for experimental research on human subjects. Women and men should have the right to control the disposal of their reproductive tissues; in the case of an embryo, the woman and her partner should have decision-making authority over embryos external to the woman's body. The CACSW's position here is based on the analogy with human tissue donations made by individuals while alive or instructions made while alive for donation after the death of an individual; an analogy may also be made between the disposal of reproductive tissues and gifts. Ethical criteria developed for the disposal of reproductive tissues also must be sensitive to the fact that patients have strongly felt and widely differing ethical convictions regarding the ultimate end of their reproductive tissues.

In those cases where a couple have jointly decided to bear responsibility for children potentially conceived through IVF/ET, they should jointly decide, prior to the commencement of their procedure, on what they desire to be done with nonimplanted embryos; their wishes should be specified in writing as part of the consent procedure. Where an individual woman has decided to undergo IVF/ET, the decision should rest with her solely. At the health facility, the individual woman or couple should be given standard consent forms which grant the choice of discarding the embryos, donating them to research, or designating donation to other infertile people. The disposal of eggs or sperm also should be governed by the patients' wishes with the same range of available options.

Another potential danger in embryo research arises from the implantation of embryos used for experimental purposes, with or without the woman's consent to experimentation. A sharp line of demarcation should be drawn between treatment and experimentation in embryo research. Experimental embryos should not be subject to reimplantation without the informed consent of the woman and the approval of the national ethics board.

Proposals:

- that all proposed experimentation in human germ-line and embryo research be reviewed by the proposed national body;
- that experimentation with human cloning and human transgenic hybrids be prohibited;
- that ethical guidelines in germ-line and embryo research distinguish between proposals regarding genetic defects and the "improvement" of the human genome, with the latter research being prohibited as unethical;
- that genetic therapies and human recombinant-DNA not be subject to patent protection;
- that embryos used in experimental research not be reimplanted in women without informed consent and appropriate approval;
- that, where eggs are extracted from women's bodies for experimental research rather than individual treatment, the procedures be considered experimental and performed only with the woman's informed, written consent;
- that decision-making regarding human reproductive tissues external to the body be deemed the prerogative of the person from whom they originated or, in the case of embryos, the joint prerogative of a woman and the partner whose gametes were used. Where the woman does not have a male partner, decisions as to the embryo will be considered her sole prerogative;
- that a public reproductive tissue agency be formed; that this agency be vested with the ultimate authority and ownership of human reproductive tissues external to the human body, subject to the decision-making powers of individuals/couples regarding the disposal of their reproductive tissues;
- that, in assisted human reproduction, the disposal of embryos be negotiated in writing with the individual woman or couple during the counselling process at the health facility. Consent forms should give those involved the choice of discarding embryos, or donating them to research or to other infertile people.

Prenatal Screening and Diagnosis

Prenatal diagnosis comprises a wide range of procedures, many of which are unequivocally good, and others of dubious value, particularly when used routinely.

Few would doubt the benefits of routine checks during pregnancy for the RH factor, for syphilis, or for gonorrhoea. However, the routine use of glucose tolerance testing for so-called gestational diabetes has no clearly established scientific worth (see "Overmedicalization of Pregnancy and Childbirth" section). The use of diagnostic ultrasound is fast becoming part of the standard of care during pregnancies in Canada, despite the paucity of data demonstrating its safety for fetal development. Indeed, the first randomized control study evaluating obstetric ultrasound was not published until more than 20 years after the technique was initially used.[76] Because existing procedures for prenatal screening and diagnosis vary widely in their risks and benefits, each must be evaluated separately for the purpose of policy recommendations or changes in a given standard of care.

Fetal genetic defects are now diagnosed through a variety of techniques, including amniocentesis, chorionic villus sampling, and alpha-fetoprotein analysis. Current diagnosis is limited almost exclusively to single-gene defects and chromosome abnormalities. Over the next generation, rapid developments in molecular genetics can reasonably be expected to expand the number of genetic defects diagnosable in prenatal and possibly in embryo testing, thereby increasing the overall utility of genetic screening. Rather than attempting to evaluate specific diagnostic techniques in current use or making projections about the future, the CACSW's remarks will address genetic counselling and the potential impact of genetic screening on people with disabilities.

Genetic counselling in Canada may parallel its development in certain parts of the United States as a distinct occupation with specific training requirements. Our comments may prove useful in directing the formation of education for genetic counsellors as well as outlining guidelines for counselling practice. Because medical doctors have no training or expertise in

counselling methods, and genetic counselling is time-consuming, responsibilities for counselling should not be in the hands of doctors; rather, they should be allocated to individuals in a separate occupational position within health facilities.

High standards of informed choice and informed consent should be set for genetic screening; as well, people undergoing this procedure need pre- and post-education and counselling. Educational counselling is needed to advise women for what sorts of genetic problems her fetus may be at risk and to negotiate what information she will want communicated with respect to test results. Counsellors should clarify in advance the predictive limits of the screening method, pointing out that the diagnosis of a genetic defect gives limited knowledge of how defects will actually be expressed in terms of mildness or severity of symptoms in specific individuals. Under no conditions should a woman's consent to a selective abortion be exacted as a prerequisite to diagnostic testing. The decision to abort or bear a child with genetic defects should remain exclusively with the woman.

Genetic screening programs need to be managed so that their implementation does not come at the expense of people with disabilities. Poor quality counselling has the capacity to spread fear of disabled people. Further, as disabled persons have stated repeatedly, difficulties of parenting children with disabilities are exacerbated by lack of social services and support; genetic screening programs must not encourage the simple attribution to genetic defects of the problems associated with being disabled or raising disabled children. Genetic counselling should be designed to resist social misunderstanding which constructs genetic screening as an alternative to employment opportunities and social services for disabled people.

During the counselling process, information should be available about existing social services for disabled children and their parents, together with relevant support groups for parents. This will enable women, who globally remain the primary caregivers to children, to evaluate the impact on their lives of raising children with disabilities. Rather than encouraging negative attitudes toward physical impairment, these types of social and emotional connections

with disabled people would constitute genetic counselling in friendly relation to human disabilities. Genetic counselling should be constructed in the awareness, not the denial, of the bodily dependency and vulnerability that are intrinsic to the human gene pool and human life cycle.

As the research and clinical capacity to detect genetic defects extends to more inherited conditions in the future, one can predict increasing problems in defining what will be considered and what not considered a genetic defect. All human beings have been estimated to carry five to ten defective genes which are not expressed; natural evolution is characterized by genetic mutation and variability. Further, a particular amino-acid sequence may be defective in some environments, but adaptive in others. The quest for genetically perfect babies is not an attainable goal in evolutionary terms; socially, it is a dangerous illusion from which genetic counselling should be completely disengaged.

Proposals:

- that access to prenatal genetic testing not be conditional on termination of pregnancy if fetal genetic defects are diagnosed;
- that genetic counselling be undertaken only by those trained in counselling practices;
- that genetic counselling provide information about adverse reactions to genetic testing, its limitations, and the difficulties of interpreting results;
- that genetic counselling encourage positive and realistic attitudes toward human disabilities and physical dependency.

Alternative Fertilization

The terms "alternative fertilization" (AF) or "donor fertilization" (DF) are preferable to "artificial insemination" (AI), an androcentric term. Canadian commentaries on alternative fertilization primarily have focused on a narrow range of themes: the rights and role of the husband/male partner, child

maintenance and inheritance rights, legitimacy of the child, access to sperm banks by single women, and medical control.

These commentaries have concentrated on protecting men in their capacity as fathers and sperm donors: little attention is paid to women's needs and concerns with respect to AF as a health service. This can be seen particularly in the discussion of access criteria and non-commercial, private arrangements, which raise the possibility of women having children who have no legally-recognized fathers. However, a variety of family forms exists in Canada today, and private arrangements between women and men regarding sperm donation have posed no threat to social stability over the course of Canadian history. Family law should not be based on socal myth.

The *Report on Human Artificial Reproduction and Related Matters*, by the Ontario Law Reform Commission, was noteworthy in its recommendation to prohibit private arangements between sperm donors and women desiring pregnancy. This suggestion, in combination with others in the report, would lead to medical control of all alternative fertilization. The Law Reform Commission of Saskatchewan raised access questions in *Proposals for a Human Artificial Insemination Act: Report to the Minister of Justice* (1981), where it was argued that the Saskatchewan *Human Rights Code* prohibits discrimination on the basis of marital and economic status. The remarks of the Law Reform Commission of Saskatchewan could now be supplemented by arguments based on the *Canadian Charter of Rights and Freedoms* in conjunction with universal accessibility criteria guaranteed under the *Canada Health Act*. Furthermore, disabled women have argued that disability per se should not constitute sufficient grounds for excluding women from AF services.

Due to the danger of communicating sexually transmitted diseases through sperm banks, the CACSW agrees with proposals to license sperm banks. Because blood and sperm testing are done by trained technicians, not doctors, and the AF process takes little time to learn, we see no technical reason why sperm banks should be placed under physicians' control, and would think such a proposal a poor expenditure of health-care resources.

Some people have objected to donor invisibility, saying that it creates the potential for inadvertent incest among children born from anonymous donors. Limiting the number of sperm donations per donor will reduce that potential.

Allowing claims of child maintenance and inheritance would be a severe disincentive to altruistic donations. Women using AF often choose this procedure precisely because they wish to avoid men claiming custody rights to children. Anonymity protects the donor and donee from legal obligations not desired by either party. Nonetheless, some women may prefer known donors, and some donors may be willing to identify themselves on a voluntary basis. Adoptive children do often become curious as to their genetic parents, and children born through AF may have the same wish. We therefore propose a two-track system of both declared and anonymous donors, with legal indemnity from rights and obligations for donors in both tracks.

Proposals:

- that private, non-commercial arrangements between women and sperm donors not be prohibited;
- that women be guaranteed access to sperm banks without discrimination based on marital status, sexual orientation, disability, race, class, or other grounds prohibited by human rights legislation;
- that sperm banks be licensed as non-commercial operations, with mandatory testing of sperm donations for sexually transmitted diseases, including AIDS;
- that individual donations be limited, and that sperm donors be granted immunity from and prohibited from claiming paternity, custody, support or other legal relationships with the child solely on the basis of having donated sperm;
- that disclosure of sperm donor personal identity be done on a voluntary basis at the time of donation; that the identity of known donors be made available to resulting children upon request at the age of majority.

Fetal Tissue Research and Implants

The use of fetal tissue should be organized on the basis of the principles outlined above regarding the disposal of human tissues external to the human body. The written consent of the woman who is to have an abortion should be obtained prior to the procedure in cases where fetal tissues might be used for research or therapeutic purposes. The donation of fetal tissues may be understood as equivalent to blood donations, that is, as a gift.

A woman's decision to have an abortion as well as access to abortion should be completely separate from her decision-making with respect to the disposal of fetal tissues. The CACSW believes that doctors who authorize abortions should be precluded from having future use of the aborted tissues for research or therapy; this rule would prevent conflict of interest. A woman placed in the position of negotiating with the same practitioner an abortion, as well as consent to the disposal of the tissues from the aborted fetus, would be open to feeling that access to abortion was contingent on her consent to tissue donation. Also, cell donors should be prohibited from making designated donations to specific individuals; this avoids possible pressure from family members.

Proposals:

- that the written consent of women authorizing the use of fetal tissues from an abortion for research/therapeutic purposes must be obtained;
- that doctors authorizing a therapeutic abortion should be institutionally distinct from medical personnel seeking consent for post-abortion uses of fetal tissues;
- that fetal tissue donations to specific individuals should be prohibited.

COMMERCIAL MARKETING OF HUMAN REPRODUCTIVE TISSUES

The buying and selling of all human tissues is an offence to the public good. The benefits of securing supplies are far outweighed by the social risks entailed. The placing of a money value on human tissues creates social conditions in which the poor are economically motivated to sell body products in violation of their health needs. In the United States, the buying and selling of human tissues has extended to ova retrieved through new conceptive technologies. It was reported in 1988 that approximately 125 U.S. medical centres offer to purchase eggs from donors for $500 (U.S.) to $1,200 (U.S.) per egg.[77] If this trend were to occur in Canada, one could envision women undergoing drug treatments and invasive egg retrieval procedures solely out of economic need. The commercial marketing of ova, sperm, and embryos should be banned by law. The ban should be extended to cover fetal tissue on the grounds that there should be no financial incentive for women to become pregnant or to terminate pregnancies at risk to their own health.

Although the implementation of this proposal might at first decrease the donation of sperm, public education programs similar to those undertaken successfully in France and Sweden would likely soon offset the short-term losses.[78] The French system of sperm banks, the Centres d'études et de conservation du sperme (CECOS), has a co-ordinated system of public education encouraging men to view donation as a public-spirited gift of value to other community members. French and Swedish men have been persuaded to donate sperm without financial incentives. We see no reason why men in Canada could not be likewise persuaded, just as Canadians have generously donated blood since World War II.

Proposals:

- that the buying and selling of human reproductive tissues be prohibited;
- that superovulation of women purely for the purpose of oocyte retrieval be prohibited.

CONTRACT MOTHERHOOD

Contract motherhood poses some of the most difficult issues for the CACSW. The basic principles outlined at the beginning of this brief are our touchstones: that women must have increased control over their lives, autonomy and self-determination in their bodily processes, truly informed choices, and equal access to resources and services. Many of the issues we struggle with today would not exist, or would take on an entirely different character, if these principles were realized. However, the real world for many women is characterized by sexual subordination, inequality, poverty, and violence. It is a world of limited choices and control. In such a world, contract motherhood has the potential of further restricting women's choices; the CACSW is committed to increasing women's options.

It has been an occasional practice cross-culturally and since time immemorial for women to bear children for other women known to them personally. These latter arrangements do not involve payment and often provide for continued interaction of all parties. The CACSW does not believe these arrangements pose problems for public values or the status of women. However, these non-commercial arrangements should be distinguished from the socially novel practice of commercial, pre-conception contracts involving third-party mediation between a woman and other parties desiring children.

The CACSW believes that women should not be made criminals if they choose to be contract mothers. Some argue that contract motherhood could become a source of employment that is no worse than many minimum-wage or ghettoized occupations typically held by women. Agencies arranging contract motherhood claim the agreements reimburse women for their work during pregnancy and childbirth, and hence should not be construed as an exchange of a baby for money, a practice prohibited as baby-selling under adoption law. However, these arguments must be evaluated against the current context and practices. Because the bulk of payments in fact take place after the baby is surrendered by the gestational mother, and payments have been reported as less for a disabled child, the actual practice does merge indistinguishably with

baby-selling. Pre-conception contracts typically remove the choice of medical doctors during pregnancy and childbirth from the gestational mother and require blanket consent, in advance, to medical procedures such as amniocentesis and Caesarian section. The principle of informed consent becomes meaningless under these common conditions of pre-conception contract.

The current reality also suggests that contract motherhood could exacerbate public perceptions of women as baby-making machines. The experience of maternal-fetal bonding during pregnancy and childbirth is unpredictable for the gestational mother. Where such bonding occurs, no woman should be expected to surrender custody of her child.

The CACSW is gravely concerned with the combined potential of IVF and cryopreservation to transfer embryos from developed countries to lesser developed countries. These technologies may facilitate a new transnationally organized process of racial subordination, specifically by white men and women over women of colour, with Third World women bearing babies for white women and men of North America and Western Europe. In future, this process has the potential of amplifying the historical pattern of Black women raising the children of white people. This pattern can be found in the United States, South Africa, and, to a lesser extent, in Canadian domestic service schemes for Caribbean immigrant women.[79]

Proposals:

- that contract mothers not be subject to criminal or civil liability;
- that the contracting gestational mother be recognized as the legal parent of her birth child, and that she have the right to retain custody of her child;
- that the Royal Commission consult with women's groups internationally on the question of North-South embryo transfer combined with contract motherhood. On the basis of this consultation, recommendations should be targetted for international agreements through the United Nations.

CONCLUSION

New conceptive technologies and genetic research hold great promise for the alleviation of human misery. However, the conditions of their current development and implementation have contributed little to the empowerment of women. Under present conditions of control and regulation, the principles of informed choice, equality of access, and bodily integrity for women consistently have been undermined.

In current circumstances, the CACSW has concluded that it doesn't make sense to be for or against NRTs. Often, the problems are not intrinsic to the technology; the most fundamental questions are about control. Women need a framework for discussion and evaluation of these technologies. In this brief, we offer minimal strategies for control over the development of NRTS and identify an urgent and ongoing need for public information and discussion. The CACSW has sought to expand the processes of democratic accountability in health care to include significant representation by women in the control and regulation of the new reproductive technologies. We have argued that innovations in assisted human reproduction need to be contextualized in a larger system of women's reproductive health care to ensure that health policy is not driven solely by curative medicine to the detriment of a preventive approach. Our tone has been sceptical because the needs of women have not been well served in either reproductive health care or, more specifically, in the new reproductive technologies.

The social debate sparked by the Royal Commission on New Reproductive Technologies has been overdue and welcome. These public discussions involving diverse constituencies need to continue likely for at least a generation to clarify the societal expectations of, and appropriate controls over, the changes taking place in human reproduction. The debate must develop in a strongly gender-sensitive direction with adequate representation of women's diverse interests. The Canadian Advisory Council on the Status of Women urges the Royal Commission to take into account the institutional structures which will be required to organize a strong women's voice in the period following

the conclusion of the Commission's work. We propose a plurality of institutional sites for vesting these women's activities. Only in this way will women's continuing needs for health protection and promotion in the field of the new reproductive technologies be ensured in the coming decades.

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APPENDIX: SUMMARY OF PROPOSALS

Preventive Reproductive Health Care (page 12)

1. that governments take steps to establish maternity benefit programs aimed at decreasing perinatal mortality;
2. that midwifery practice be legally recognized and that community-based midwifery services be integrated into the health-care system.

Overmedicalization of Pregnancy and Childbirth (page 14)

1. that a national inquiry be called to investigate Canadian medical practices for pregnancy and birth;
2. that community-based reproductive health-care clinics be funded to provide an alternative to acute-care management of pregnancy and childbirth;
3. that where/as advocated by Aboriginal women's groups, the policy of routine evacuation of Aboriginal women for childbirth to secondary- and tertiary-care hospitals be discontinued;
4. that where/as advocated by Aboriginal women's groups, the federal government provide funding for birth centres in all Aboriginal communities and train community midwives to provide care during pregnancy and childbirth.

Misperception of the Fetus as Autonomous (page 16)

1. Reproductive choice is an equality issue. In our society, women become pregnant, bear and raise children under conditions of inequality. Partial remedies for these inequities include: increased child care facilities; economic self-sufficiency for women; research to develop safe methods of contraception; access to a full range of reproductive health services; development of information, resources and services to support family planning and birth control; sex education; and access to abortion.
2. A pregnant woman has the right to determine the best medical treatment for herself or the fetus she is carrying, in consultation with advisors of her choice and without threat of third party intervention or obstruction. No woman should be penalized for making a decision which she believes furthers her physical and mental health, the health of her children, the health of her family as a whole, or the health of any fetus she is carrying.

3. A pregnant woman who has made the decision to have an abortion should have access to abortion services at the earliest opportunity, and should not be forced into a late term abortion or denied access altogether by reason of obstructive diagnostic procedures and practices, financial impediments, geographic location or legal and quasi-legal proceedings. Reproductive health services and abortion must be available to women equitably throughout Canada, and be funded completely by provincial health insurance plans, in keeping with the principles of universality, accessibility and comprehensiveness as stated in the Canada Health Act.

Health Policy (page 18)

1. that the federal government fund basic epidemiological research on normal fertility, subfertility, and infertility to determine incidence and cause differentiated by gender;
2. that infertility be defined, for heterosexual couples, as the inability to conceive a viable pregnancy after two years of unprotected intercourse;
3. that the Commission, in recognition of the fact that current definitions of infertility presuppose male-female couples, consult with lesbian and single women to adopt a definition of infertility appropriate to their circumstances;
4. that health ministries in all jurisdictions, together with medical associations, limit the medical indications for IVF and related conceptive technologies;
5. that IVF and related procedures be limited to a maximum of four ovulation induction cycles.

Prevention of Infertility (page 21)

1. that governments, in each fiscal year, not spend more on IVF and related technologies than on public health research and services for the prevention of infertility.

Contraceptive History (page 22)

1. that the manufacturers of contraceptive drugs and devices be required to indicate the following clearly on the packaging: failure rates, secondary effects, and the expiry date of their products;
2. that pelvic inflammatory disease be classified as a federally reportable disease;
3. that the federal government fund research on intrauterine devices as a risk factor for infertility;
4. that the federal government give high priority to funding research into male and female contraception which is both safe and effective, with safety interpreted to include the prevention of infertility.

Sexually Transmitted Diseases (page 22)

1. that governments support public education and school programs on family planning, sex education, contraception, and sexually transmitted diseases, and that periodic evaluation of such programs be carried out by qualified personnel;
2. that provincial/territorial medical associations, in cooperation with health ministries, encourage physicians to be more consistent in recording instances of reportable STDs to produce a more accurate assessment of their incidence.

Occupational Hazards to Reproductive Health (page 23)

1. that the federal government amend the Canada Labour Code to prevent discrimination in hiring, job placement, promotion, and other conditions of employment based on factors related to reproductive physiology, such as reproductive capacity, pregnancy, or childbirth;
2. that the Canadian Centre for Occupational Health and Safety establish a statistical database recording the type and degree of exposure to reproductive hazards in Canada and an estimation of the worker population at risk for each identified hazard;
3. that the federal government make greater efforts to increase federal/provincial/territorial consultation and information-sharing and, through such efforts, attempt to establish a uniform high level of standards in occupational health and safety;
4. that standards setting out permissible levels of exposure to workplace hazards should:
   a) establish a single standard for each hazard which would ensure maximum protection for the most susceptible worker of any age and either sex;
   b) ensure that laboratory or other testing of all new substances or processes include screening for teratogenicity, mutagenicity, carcinogenicity, and evidence of effects on lactation before introducing them into the workplace;
   c) be measurable, understandable, and capable of general enforcement;
   d) be re-examined on a regular basis;
5. that the federal government ensure that research into all aspects of occupational health hazards affecting reproductive physiology be stimulated by:
   a) specifically allocating increased budgetary and staff resources for this purpose to any federal department/agency/responsibility centre involved in occupational health and safety issues;
   b) specifying that where federal money to carry out occupational health studies on humans is granted to any research body or individual, the research design and the results must include both female and male workers when both sexes are employed in the particular workplace;
   c) designating research money to be used in studies of employment sectors with a high proportion of female workers.

Counselling Services (page 25)

1. that governments fund infertility counselling services;
2. that infertility counselling services be independent of social and medical programs for the management of infertility. Funding for these services should not come from clinics or industry.

Standardization and Collection of Information (page 26)

1. that a national system of standardized, mandatory reporting for infertility and NRTs be developed to include data on research, services, techniques, and treatments;
2. that a national patient and treatment register for IVF and related conceptive technologies be established, as set out in the recommendation in the section "Evaluation: Access and Cost".

Standards of Evaluation (page 27)

1. that government funding be made available to encourage biostatistical research on appropriate research methods for evaluating NRTs.

The System of Ethics Review (page 28)

1. that local reproductive health committees be formed in all health facilities where research and treatments affecting human reproduction take place. Members of reproductive health committees should be chosen independently of service providers, and should consist of at least 50% women. The mandate of the reproductive health committees would include ethical reviews of research, the ethics of service provision, and the planning and monitoring of reproductive health services in their institutions;
2. that a national body be established to review and approve research proposals, set ethical standards, set national standards of informed consent for NRT research and therapy, standardize data collection on NRTs, and monitor service access and provision.

Monitoring Reproductive Pharmaceuticals (page 31)

1. that the Bureau of Human Prescription Drugs give public notice of all pre-clinical drug submissions and new drug submissions;
2. that the public have access to all information in pre-clinical drug submissions and new drug submissions;
3. that physicians be required by law to obtain the informed consent of patients in cases where a pharmaceutical is being prescribed in a way not approved by the Health Protection Branch;

4. that increased funding be provided to the drug adverse reaction program to expand its staff and to publicize among physicians the importance of reporting drug adverse reactions.

Women's Reproductive Health Centres (page 33)

1. that the federal government fully reinstate funding for the advocacy, education, research, and publication functions of women's groups;
2. that the federal government support an independent, organized voice for women's health protection and promotion in reproductive health care by funding a network of women's reproductive health centres across Canada.

IVT/EF and Related Conceptive Technologies (page 35)

1. that IVF be classed as experimental, funded through research budgets, and subject to the high standards of informed choice and consent outlined in the Nuremberg Code and the Helsinki Declaration.

Evaluation: Efficacy (page 36)

1. that research be commissioned to compare efficacy rates in the various subclasses of infertility for women who have undergone IVF/ET and groups consisting of nontreated women as well as women receiving more standard forms of therapy;
2. that, for reasons of safety, efficacy, and cost, the indications for IVF/ET be restricted to those with the best success rates and that male factors not be considered an indication for this procedure;
3. that a national, compulsory standard of reporting IVF/ET and GIFT success rates to health consumers based on live births per 100 stimulation cycles be adopted. Information on efficacy rates should be reportable and mandatory. Summary statistics should be made available to the public;
4. that standards of personnel and practice for IVF clinics be established, and that clinic licensing be made mandatory.

Evaluation: Safety (page 38)

1. that a national IVF/GIFT patient and treatment register be established, with mandatory reporting by all IVF/GIFT clinics of complications and interventions during pregnancy and childbirth, perinatal and neonatal mortality and morbidity, and pharmaceutical use.

Evaluation: Access and Cost (page 39)

1. that women be guaranteed access to NRTs without discrimination based upon marital status, sexual orientation, disability, race, or socio-economic status;
2. that access to IVF/ET and GIFT be restricted to those women whose medical indications show the greatest likelihood of success and who clearly would not benefit from other forms of infertility services.

Genetic Engineering and Embryo Research (page 40)

1. that all proposed experimentation in human germ-line and embryo research be reviewed by the proposed national body;
2. that experimentation with human cloning and human transgenic hybrids be prohibited;
3. that ethical guidelines in germ-line and embryo research distinguish between proposals regarding genetic defects and the "improvement" of the human genome, with the latter research being prohibited as unethical;
4. that genetic therapies and human recombinant-DNA not be subject to patent protection;
5. that embryos used in experimental research not be reimplanted in women without informed consent and appropriate approval;
6. that, where eggs are extracted from women's bodies for experimental research rather than individual treatment, the procedures be considered experimental and performed only with the woman's informed, written consent;
7. that decision-making regarding human reproductive tissues external to the body be deemed the prerogative of the person from whom they originated or, in the case of embryos, the joint prerogative of a woman and the partner whose gametes were used. Where the woman does not have a male partner, decisions as to the embryo will be considered her sole prerogative;
8. that a public reproductive tissue agency be formed; that this agency be vested with the ultimate authority and ownership of human reproductive tissues external to the human body, subject to the decision-making powers of individuals/couples regarding the disposal of their reproductive tissues;
9. that, in assisted human reproduction, the disposal of embryos be negotiated in writing with the individual woman or couple during the counselling process at the health facility. Consent forms should give those involved the choice of discarding embryos, or donating them to research or to other infertile people.

Prenatal Screening and Diagnosis (page 45)

1. that access to prenatal genetic testing not be conditional on termination of the pregnancy if fetal genetic defects are diagnosed;
2. that genetic counselling be undertaken only by those trained in counselling practices;
3. that genetic counselling provide information about adverse reactions to genetic testing, its limitations, and the difficulties of interpreting results;
4. that genetic counselling encourage positive and realistic attitudes toward human disabilities and physical dependency.

Alternative Fertilization (page 47)

1. that private, non-commercial arrangements between women and sperm donors not be prohibited;
2. that women be guaranteed access to sperm banks without discrimination based on marital status, sexual orientation, disability, race, class, or other grounds prohibited by human rights legislation;
3. that sperm banks be licensed as non-commercial operations, with mandatory testing of sperm donations for sexually transmitted diseases, including AIDS;
4. that individual donations be limited, and that sperm donors be granted immunity from and prohibited from claiming paternity, custody, support or other legal relationships with the child solely on the basis of having donated sperm;
5. that disclosure of sperm donor personal identity be done on a voluntary basis at the time of donation; that the identity of known donors be made available to resulting children upon request at the age of majority.

Fetal Tissue Research and Implants (page 50)

1. that the written consent of women authorizing the use of fetal tissues from an abortion for research/therapeutic purposes must be obtained;
2. that doctors authorizing a therapeutic abortion should be institutionally distinct from medical personnel seeking consent for post-abortion uses of fetal tissues;
3. that fetal tissue donations to specific individuals should be prohibited.

Commercial Marketing of Human Reproductive Tissues (page 51)

1. that the buying and selling of human reproductive tissues be prohibited;
2. that superovulation of women purely for the purpose of oocyte retrieval be prohibited.

Contract Motherhood (page 52)

1. that contract mothers not be subject to criminal or civil liability;
2. that the contracting gestational mother be recognized as the legal parent of her birth child, and that she have the right to retain custody of her child;
3. that the Royal Commission consult with women's groups internationally on the question of North-South embryo transfer combined with contract motherhood. On the basis of this consultation, recommendations should be targetted for international agreements through the United Nations.

Canadian
Advisory Council
on the Status of Women

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